

Minimum Competency Recommendations for Programs that Provide Rehabilitation Services for Persons with Disorders of Consciousness: A Position Statement of the American Congress of Rehabilitation Medicine and the National Institute on Disability, Independent Living and Rehabilitation Research Traumatic Brain Injury Model Systems

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Abstract

Persons who have disorders of consciousness (DoC) require care from multidisciplinary teams with specialized training and expertise in management of the complex needs of this clinical population. The recent promulgation of practice guidelines for patients with prolonged DoC by the American Academy of Neurology (AAN), American Congress of Rehabilitation Medicine (ACRM), and National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) represents a major advance in the development of care standards in this area of brain injury rehabilitation. Implementation of these practice guidelines requires explication of the minimum competencies of clinical programs providing services to persons who have DoC. The Brain Injury Interdisciplinary Special Interest Group of the ACRM, in collaboration with the Disorders of Consciousness Special Interest Group of the NIDILRR-Traumatic Brain Injury Model Systems (TBIMS) convened a multidisciplinary panel of experts to address this need through the present position statement. Content area-specific workgroups reviewed relevant peer-reviewed literature and drafted recommendations which were then evaluated by the expert panel using a modified Delphi voting process. The process yielded 21 recommendations on the structure and process of essential services required for effective DoC-focused rehabilitation, organized into four categories: Diagnostic and Prognostic Assessment (four recommendations), Treatment (eleven recommendations), Transitioning Care/Long Term Care Needs (five

recommendations), and Management of Ethical Issues (one recommendation). With few exceptions, these recommendations focus on infrastructure requirements and operating procedures for the provision of DoC-focused neurorehabilitation services across subacute and post-acute settings.

Key words: disorders of consciousness, rehabilitation, health services, best practices, outcome

Abbreviations: DoC: disorders of consciousness; DNR: do not resuscitate; MCS: minimally conscious state; QI: quality improvement; UWS: unresponsive wakefulness syndrome

The American Congress of Rehabilitation Medicine (ACRM) and the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR), which funds 16 Traumatic Brain Injury Model System centers (TBIMS), have been instrumental in developing approaches to clinical management of persons with disorders of consciousness (DoC) caused by acquired brain injury. Together with the American Academy of Neurology (AAN), ACRM and NIDILRR recently published updated evidence-based practice guidelines on this topic.¹ There remains a need to establish a consistent approach to care among brain injury programs that provide rehabilitation services to patients who have DoC. The DoC Special Interest Groups (SIGs) of ACRM and NIDILRR recognized the need for minimum competency recommendations to guide provision of rehabilitation care for patients who have DoC. *The proposed recommendations, informed by best practices, empirical evidence and expert consensus, address the essential staff, knowledge, skills and services required for clinical management of this population.*

Following review of the current state of rehabilitative care for patients who have DoC, and a description of the process used, we present 21 minimum competency recommendations. Each recommendation is preceded by a specific management question concerning, 1) diagnosis and prognosis, 2) treatment, 3) transitional and long-term care planning or 4) management of ethical issues, followed by supporting text.

The proposed recommendations are intended for use by program administrators, clinicians and payors involved in the care and authorization of services for persons who have DoC, respectively. The recommendations are aligned with the Medicare Payment Advisory

Commission's 2019 Report to Congress on Medicare and Proposed Reforms to the Health Care Delivery System,² which calls for a two-tiered regulatory approach to establishing provider competencies. Under such a system, all post-acute care (PAC) providers would be expected to meet a common set of requirements that establish basic competencies necessary to treat the typical PAC patient. Providers who treat patients with specialized or very high care needs- such as those with acquired DoC, would be required to meet a second tier of requirements that match the specialized care needs of the population. The current recommendations suggest a comprehensive framework for evaluating PAC programs that serve the complex care needs of patients who have DoC. We frame these recommendations in terms of required capacities and infrastructure rather than in terms of specific facility types (e.g., Inpatient Rehabilitation Facility- IRF, Skilled Nursing Facility- SNF, Long-Term Acute Care Hospital- LTACH) in view of the changing nature of post-acute care and the desire to focus on the functionally important elements of optimal care. With few exceptions, the recommendations do not call for use of specific assessment methods or interventions; rather, they describe the basic infrastructure and operating procedures that should be deployed for evaluation, treatment and provision of services. As new evidence accumulates, more specific recommendations will supplant the current ones. Although the proposed recommendations are directed toward IRFs, they are generally applicable to other settings providing neurorehabilitation services, including acute care hospitals, LTACHs and SNFs.

Background and Rationale

Following emergence from coma, patients often transition into a vegetative state (VS), also known as unresponsive wakefulness syndrome - UWS),³ or minimally conscious state (MCS).⁴

In VS/UWS, there are periods of wakefulness but no discernible evidence of self or environmental awareness. MCS is characterized by inconsistent but definitive evidence of volitional behavior. These conditions, which may be transient or permanent, pose some of the most complex clinical management problems encountered in medicine and place heavy resource demands on the healthcare system as individuals who have DoC are surviving longer. Annual US prevalence rates exceeding 300,000 cases (VS/UWS and MCS together)^{3,5} are likely underestimated due to a lack of surveillance systems outside of acute care and IRF settings.⁶

Admission policies and cost-control measures imposed by payors have limited access to comprehensive rehabilitation for patients who have DoC. Admission to acute IRFs is often denied or permitted only briefly, contingent upon documentation of rapid functional improvement. For example, the InterQual IRF admission guidelines require patients to be “Rancho Level III [roughly MCS] and evolving” to qualify.^{7(p. RHB-20)} Moreover, reimbursement to SNFs is typically insufficient to support multidisciplinary rehabilitation and specialty medical monitoring that were previously possible in the fee-for-service environment. Consequently, many patients who have DoC are discharged directly from acute care to healthcare settings lacking expertise to provide specialized care.⁸

European studies suggest that when patients who have DoC are transferred directly from acute care to a SNF (the prevailing model), care may be suboptimal, and that early-continuous rehabilitation within a specialized care setting results in better outcomes and cost savings.^{9,10} A multi-center U.S.-based prospective cohort study of 396 patients with DoC receiving specialized IRF-based care found that over 20% emerged from post-traumatic amnesia (PTA) and

demonstrated significant improvements in functional status during their rehabilitation stay.¹¹ Unfortunately, referrals from SNFs to IRFs are uncommon, and acute care hospitals and SNFs generally lack the expertise to conduct specialized assessments required for this population. With high rates of diagnostic error among non-specialized providers,¹²⁻¹⁴ and generally imprecise¹⁵ prognostication, acute care facilities may not refer eligible patients who may benefit from comprehensive IRF services.

Patients who have DoC also carry a high rate of medical comorbidities and secondary complications¹⁵ (e.g., hydrocephalus, non-convulsive seizures) associated with poor outcomes.¹⁷ Evidence suggests that achieving and maintaining medical stability is the result of active management rather than the passage of time¹⁶ and may decrease overall healthcare costs.¹⁸ Complications and comorbidities associated with DoC are best managed by specialists in settings that routinely provide care for such patients.

Long-term functional outcome defies accurate prognostication early after brain injury, although precision improves with time.¹⁵ Consequently, it may not be clinically or ethically appropriate to limit care early after injury, particularly when these limits are based on early prognostic signs. Most caregivers want treatment to continue as long as uncertainty remains. Unfortunately, by the time accurate prognostication is feasible, most patients are no longer in the care of specialists with the knowledge to assess and discuss prognosis with family members. The current system too often fosters premature termination of treatment based on overly-pessimistic early predictions yet may also lead to continued aggressive care after treatment is futile.

Despite these obstacles, recent evidence indicates that approximately 30-40% of persons admitted to IRF in VS/UWS or MCS recover functionally-important behaviors such as consistent command-following, intelligible speech and reliable communication prior to discharge.^{19,20} Long-term outcome studies demonstrate that at least 20% go on to attain independence in community and vocational activities within five years of injury,^{19,21} and the total proportion achieving independence increases further by 10 years post-injury.²² These findings suggest that patients who have DoC should be cared for by multidisciplinary teams with specialized training to manage their complex needs.²

Methodology for Developing Minimum Competency Recommendations

In March of 2013, the ACRM and NIDILRR DoC SIGs convened a multidisciplinary author panel with expertise in DoC to provide guidance to IRFs that provide rehabilitation services for persons who have DoC. The panel drafted an outline describing the target population and intended audience, rationale for establishing recommendations, areas of focus and future directions. Five workgroups were assembled- diagnosis, prognosis, treatment, transitional and long-term care planning, management of ethical issues, each with two co-leaders. The diagnosis and prognosis workgroups were subsequently merged due to content overlap. Workgroups reviewed relevant peer-reviewed literature and drafted recommendations in each area.

A modified Delphi voting process was used to determine the strength of each recommendation. Consensus was reached when 80% of the author panel indicated agreement. Authors were invited to suggest revisions to any recommendation not initially supported. Feedback was collated and

reviewed by the author panel prior to the next round of voting. All recommendations achieved consensus within the *a-priori* cutoff of 3 voting rounds.

After all recommendations were finalized, workgroups drafted text describing the rationale and supporting evidence. A professional medical writer, who had no role in development of the recommendations, reviewed and edited the supporting text and references. The senior authors (JTG, JW, RN-R) completed further edits to reduce the length of the manuscript. An Audit Checklist was also developed by the authors to guide providers, payors and consumers who wish to evaluate a particular DoC program's compliance with the recommended program components (see Appendix 1). The Checklist is organized around the procedures, assessment schedule and professional disciplines required to provide evidence-informed patient care and perform program evaluation. This tool is not intended to prescribe specific methods for implementing the recommendations, but rather seeks to ensure that critical areas of care are addressed and reviewed on a regular basis by appropriate personnel. The Checklist can be used at either the program level (for program evaluation) or for the individual patient (for care planning) and, as such, may be modified accordingly. Appendix 2 summarizes the 21 recommendations by domain and Appendix 3 defines key terms.

After the final draft of the manuscript was approved by all members of the author panel, it was forwarded to the ACRM Evidence and Practice Committee (EPC) and NIDILRR for concurrent review. The manuscript was approved by NIDILRR on September 3, 2019, approved by the ACRM EPC on October 25th, 2019 and endorsed by the ACRM Board of Governors on (February 6, 2020).

RECOMMENDATIONS

Diagnostic and Prognostic Assessment

How should diagnostic and prognostic assessment of persons with disorders of consciousness be approached?

Recommendation 1: Specialized programs for patients who have DoC should adopt a systematic approach to diagnostic and prognostic assessment that relies on a careful review of the history, recent structural imaging data, and serial testing with validated behavioral measures.

Behavioral assessment remains the “gold standard” for evaluation of patients who have DoC¹² and validated neurobehavioral instruments have been shown to be more accurate in establishing diagnosis when compared to other methods.²³ Serial testing should be performed to minimize misdiagnosis that may arise from spontaneous fluctuations in arousal and other causes of behavioral variability.²⁴⁻²⁶ Computed tomography (CT) or magnetic resonance imaging (MRI) should be performed early in the course of recovery, or anytime late complications (e.g., post-traumatic hydrocephalus), which may mask conscious awareness and slow recovery, are suspected.^{27,28}

What factors should be considered when establishing diagnosis?

Recommendation 2: Differential diagnosis among DoC (i.e., coma, VS/UWS, MCS) should be based on published, evidence-based guidelines, rely on diagnostic procedures that have acceptable reliability and validity, and consider common confounding factors such as sedating treatments and underlying sensory, motor, or cognitive impairments.

The approach to diagnosis should be guided by the recently-released AAN-ACRM-NIDILRR clinical practice guidelines for management of patients who have DoC.¹ To reduce misdiagnosis, protocols should be in place to identify and treat confounding factors such as occult medical complications (e.g., infection, seizures, hydrocephalus), co-morbid cognitive (e.g., aphasia, apraxia), motor (e.g., spasticity, paresis) or sensory deficits (e.g., blindness/deafness) and adverse environmental influences (e.g., sedating medications, restraints, noise level) that may impede or mask behavioral responses.^{29,30}

What factors should be considered when establishing prognosis for recovery of consciousness and functional improvement?

Recommendation 3: Prognostication in patients who have DoC should consider the best available evidence. When formulating prognosis, one must consider: (a) predictors used, (b) outcome of interest; (c) time post-injury when the predictor is applied (e.g., 2 weeks, 3 months, 60 months), (d) time post-injury when the outcome of interest will be assessed (e.g., 6 months, 12 months, 60 months); and (e) degree of precision associated with the prognostic forecast.

The AAN-ACRM-NIDILRR DoC practice guidelines¹ should be consulted for prognostic guidance related to diagnosis (VS/UWS vs MCS), mechanism of injury (traumatic vs non-traumatic injury) and outcome of interest (recovery of consciousness vs function). Although a variety of outcome predictors have been identified, most have wide confidence intervals and the predictive utility of a given indicator changes as the condition evolves. As spontaneous recovery slows over time, prognostic uncertainty decreases and predictions become more accurate. A staged approach is recommended, in which prognosis is updated when clinical (e.g., transition from VS/UWS to MCS) and temporal (e.g., 3, 6 and 12 months post-injury) milestones are met.

What information should be provided to caregivers, families and professionals when discussing diagnosis and prognosis in persons with disorders of consciousness?

Recommendation 4: Communication of diagnosis and prognosis should ensure that the clinical information provided (i.e., diagnostic features, prognostic indicators) is understandable and the limits of certainty afforded by the available evidence are described.

In view of the complexity and uncertainty inherent in evaluating patients who have DoC, a clinician with specialized knowledge, training and experience should be involved in formulating and communicating prognostic information. It is important to first determine how much information the family wants to know and what outcomes they view as important. Prognostic information should be communicated with sensitivity, attention to stage of recovery, possible outcome trajectories and the level of certainty) afforded by the supporting evidence.

Comprehension of prognostic information can be fostered by adhering to effective practitioner communication principles, such as those outlined in the COMFORT model.³¹⁻³³ Language should be simple and direct, avoid medical jargon or euphemisms, and never force the recipients to relinquish hope. Knowledge gaps and factors complicating prognostic certainty should be acknowledged and addressed by seeking outside consultation where possible.

Treatment

What professional disciplines are required, and how should they be integrated, to operate a specialized program for patients who have DoC?

Recommendation 5: Rehabilitation services in a DoC program should be provided by a multidisciplinary team of brain injury professionals whose members include, but are not limited to, physicians, psychologists, physical therapists, occupational therapists, speech language pathologists, nurses, and social workers, and whose efforts are focused on individualized cross-disciplinary treatment goals that enhance health, mobility, self-care, communication and participation.

What specialized medical expertise is required to manage the most common medical complications experienced by patients who have DoC?

Recommendation 6: An attending physician must be available on-site at least 5 days per week (with continuous on-call coverage) to oversee medical management; programs that accept patients on ventilators should additionally have a specialist in pulmonology on site. The program should have established procedures for obtaining timely consultations from consultants in additional specialties not represented by the attending physician, including internal medicine, physiatry, neurology, neurosurgery, infectious disease, gastroenterology, ophthalmology, and otolaryngology, and established relationships with specialists in each of these areas. Standard procedures must be in place to transfer patients with severe or life-threatening conditions to acute care or ICU services emergently.

Given the complexity of DoC, a multidisciplinary team with expertise in brain injury is required to provide the rehabilitative services necessary.³⁴ Multidisciplinary care produces greater functional gains in mobility, daily activities and cognition, reduces caregiver distress,^{35,36} and decreases length of stay and rehospitalization.³⁷ These differences are likely attributable to greater access to DoC specialists and higher-intensity rehabilitation.³⁷ Multidisciplinary

treatment goals should center on facilitating arousal, promoting purposeful behavior, fostering effective communication and restoring self-care.³⁸

Patients who have DoC experience a high rate of medical complications, highlighting the need for close monitoring and expert medical care.¹⁶ Active medical management and inpatient rehabilitation reduce the rate of medical complications,¹⁶ visits to the emergency department and rehospitalization.³⁵ Some complications require access to both medical (e.g., physiatry, neurology, psychiatry, neuroophthalmology) and non-medical (e.g., audiology, neuropsychology) specialties.^{16,39}

What healthcare regimens should be incorporated into routine clinical management to maintain health?

Recommendation 7: Care regimens intended to promote physical health and mitigate complications should be initiated immediately upon admission, updated at least weekly and streamlined where possible to reduce the burden of future care. At a minimum, these regimens should focus on adequate nutrition; respiratory hygiene and aspiration risk; bladder and bowel management; skin integrity; contracture prevention, positioning and tone management; prevention of venous thrombosis; and optimizing sleep/wake patterns.

Patients who have DoC often manifest deranged metabolomics, blood-brain barrier compromise, altered neuroplasticity, degenerative changes,⁴⁰⁻⁴³ orthopedic sequelae⁴⁴ and immobility,⁴⁵ placing them at risk for multi-system complications, which can compromise outcome. Care providers should be vigilant to complications by initiating care regimens designed to maintain physical health at the time of admission. Early implementation of preventive measures improves functional recovery and reduces cost.^{9,10,46,47} Care regimens should be reviewed weekly and updated based

on multidisciplinary team consensus. When patients approach the point of transition to a longer-term care facility or home, the care regimen should be re-assessed to determine which therapies and supports remain necessary and which can be streamlined or discontinued to simplify future care (e.g., substituting longer-acting medications, removing an endotracheal tube).^{48,49}

What routine evaluations should occur upon admission to identify barriers to recovery or to its detection?

Recommendation 8: On admission, a comprehensive neurosensory examination should be performed to evaluate for previously unrecognized auditory, visual, somatosensory and motor impairments; prescribed medications should be reviewed so those with potentially sedating properties can be stopped or replaced with less sedating alternatives where possible; and brain imaging studies to define residual neuropathology and screen for late complications should be reviewed and updated if appropriate.

Neurosensory assessment and structural brain imaging studies (CT or MRI) should be reviewed, or, if unavailable, performed on admission to identify potential sensory (e.g., blindness, deafness, somatosensory loss), motor (e.g. paralysis, weakness) and cognitive impairments (e.g., aphasia, apraxia) that may mask behavioral evidence of consciousness.^{50,51} Commonly-prescribed medications for pain, seizures, spasticity and sleep should be reviewed to minimize the risk of sedation, which may negatively affect arousal and behavioral responsiveness.⁵²

When bedside examination findings remain ambiguous, functional imaging (e.g., single photon-emission computed tomography (SPECT), positron emission tomography (PET), functional MRI (fMRI)) and electrophysiological studies (e.g., electroencephalography (EEG), evoked potentials

(EP), event-related potentials (ERP)) may be considered to detect “covert” signs of consciousness revealed by specific patterns of brain activation.⁵³⁻⁵⁶

What additional evaluations should be considered for patients who show decline in function?

Recommendation 9: Programs should have protocols that initiate timely medical evaluation in response to a decline or plateau in clinical status and function, or in the presence of clinical conditions that present risks for worsened outcomes. These evaluations should address possible disorders including new intracranial complications, subclinical seizures, occult infections, metabolic disturbances, or adverse medication effects, and will typically entail neuroimaging, electrophysiological assessments, laboratory studies, and/or comprehensive medication review.

Patients who have DoC are at particularly high risk for seizure, spasticity, hydrocephalus, and urinary tract infections,¹⁶ which predispose to rehospitalization,³⁷ worse outcome at 1 year⁵⁷⁻⁵⁹ and premature death.⁶⁰ Assessment and treatment protocols should be in place to promote early detection and management of these problems. Programs should have access to EEG monitoring to recognize occult seizures, CT imaging to detect new lesions or hydrocephalus, hormonal and metabolic assessment for endocrine dysfunction, workups for occult infections and regular medication review to identify sedating agents. When resources require prioritization, assessments should focus first on patients who have improved then declined, then patients who have plateaued, and finally patients who are improving.

What interventions should be considered to optimize current function and facilitate neurologic and functional recovery?

Recommendation 10: Environmental factors (e.g., positioning, lighting, time of day, level of stimulation, distractions and restraint) that may influence arousal and neurocognitive performance should be systematically evaluated for their impact on behavior.

Behavioral responsiveness and functional status can be influenced by environmental conditions. Poor positioning and physical restraints may limit detection of purposeful movement, ambient noise may distract attention and improper lighting may adversely affect sleep-wake cycles.²⁹ DoC programs should regularly assess the potential impact of the environment on behavior and make adjustments accordingly to optimize interpersonal interactions and participation.

Recommendation 11: Pharmacologic or other interventions that have been systematically reviewed and found to be efficacious in enhancing arousal, behavioral responsiveness or rate of recovery should be strongly considered when developing a plan of care. Other interventions, whose efficacy or inefficacy has not been determined in such studies, can be considered for use when the risk of adverse effects is low and a reasonable plan is in place to determine the positive and negative effects of treatment in the individual.

Few medications have sufficient evidence in controlled trials to support clinical use in promoting arousal, responsiveness and function. Amantadine hydrochloride, a selective uncompetitive NMDA receptor antagonist, is the only medication recommended for clinical use in the AAN-ACRM-NIDILRR DoC practice guidelines.¹ A multicenter, prospective, randomized controlled trial (RCT) involving rehabilitation inpatients with traumatic DoC between 4 and 16 weeks post-injury found that amantadine increased rate of functional recovery without adverse effects when compared to placebo.²⁰ Zolpidem, a nonbenzodiazepine sedative/hypnotic, may be considered case by case based on a prospective placebo crossover trial that found clear but transient

paradoxical improvement in consciousness following a single dose in approximately 5% of patients treated.⁶¹⁻⁶² No other medications or non-pharmacologic interventions have demonstrated sufficient efficacy in well-controlled trials to recommend use in clinical practice.^{1,63}

Clinicians should recognize that establishing the efficacy of any therapeutic intervention in an individual patient is difficult early after injury because the natural history of recovery is variable. When unproven medications are considered, the designated surrogate decision-maker should be involved in the discussion, a protocol should be in place to establish that baseline performance is relatively stable, treatment effects are dose-dependent and adverse effects are monitored.⁶⁴

Recommendation 12: A variety of strategies, technologies and adaptive equipment should be available to enhance the detection of emerging neurobehavioral capacities and augment their transformation into functional abilities such as communication and environmental interactions. There should be a systematic approach to assessment of patient capacities that can guide selection of appropriate technology, and to assessing the functional impact of the technology selected.

Programs serving patients who have DoC should have assistive technologies to aid receptive and expressive sensorimotor processes involved in communication and environmental control.^{65,66} Prior to implementing assistive technologies, an evaluation should be conducted to demonstrate that the sensory, motor, cognitive and language skills required to effectively execute the behavioral response(s) required to use the device functionally (e.g., answer questions with a switch that activates a yes/no signal) are adequately preserved.⁶⁷

How should rehabilitative interventions intended to enhance recovery be monitored?

Recommendation 13: When monitoring recovery in individual patients, validated measures should be used to establish level of performance at baseline, rate and trajectory of recovery, degree of disability, and response to individualized treatment. The frequency of assessment and review of results should be sufficient to address the question(s) of interest.

As patients progress through rehabilitation, validated assessment methods should be used to monitor progress across multiple outcome domains, including arousal, pain, mobility and communication ability.^{23,38} Assessments should be repeated regularly to determine the rate of recovery and, as performance reaches ceiling on a particular instrument, transition to measures capable of capturing more complex functions.⁶⁸ When behavioral responses are ambiguous or infrequent, Individualized Quantitative Behavioral Assessment (IQBA) can be considered to address case-specific questions in a standardized manner.^{69,70} The frequency of assessment depends on the nature of the problem, measurement variability, magnitude of effect and speed of onset of the treatment being assessed. It may not be possible to determine the effectiveness of a medication in the context of slow and variable background recovery, especially when the medication has a gradual onset of action and must be slowly titrated.

How should rehabilitation programs specializing in management of patients who have DOC ensure provision of high-quality rehabilitation care?

Recommendation 14: DOC programs should have a well-defined plan for staff education and training to ensure that assessment and treatment interventions designed for patients and caregivers address primary areas of need and are based on the best available evidence.

Recommendation 15: Systems for quality improvement (QI) that rely on consistent assessment measures and pre-specified performance benchmarks should be in place. Review of QI data

should be performed at least twice each year. QI measures may include commercially available assessments, locally-developed assessments, or a combination of both. Program performance benchmarks should be established to address patient outcomes, caregiver needs, and operational program processes.

Clinical staff require specialized training as most graduate-level training programs do not include course curricula or practicum experiences specific to patients who have DoC. Programs serving persons who have DoC should provide education and training that is continually updated in accordance with current practice guidelines to ensure competence in the knowledge and skills needed to effectively care for patients who have DoC and their caregivers. In addition, Continuous Quality Improvement (CQI) processes should be in place to evaluate performance across identified program benchmarks.⁷¹

Transitioning Care/Long Term Care Needs

Under what circumstances should a patient be transitioned to comprehensive brain injury rehabilitation?

Recommendation 16: When patients in DOC programs demonstrate recovery of consciousness, treatment goals should shift to support rehabilitation interventions designed to promote greater independence in mobility, self-care, communication and other functional goals.

Full recovery of consciousness occurs when reliable communication (i.e., accurate and consistent verbal or gestural “yes/no” responses) or functional object use (i.e., demonstration of appropriate use of at least two common objects) is demonstrated.³ When these milestones are achieved,

treatment goals should shift from a focus on arousal and behavioral responsiveness to strategies that promote independent mobility and resumption of basic activities of daily living. A recently-completed RCT found that manualized ADL retraining incorporating errorless and procedural learning strategies resulted in significantly greater functional independence (i.e, FIM change) at time of PTA emergence⁷² and was more cost-effective⁷³ as compared to deferring ADL training until continuous memory returned.

Under what circumstances should transition to a less intensive level of care occur?

Recommendation 17: After an adequate period of assessment, transition to a less intensive care setting should occur when the pace of change suggests that functional abilities, rehabilitation goals, and medical needs are not changing substantially or anticipated to change in the near-term and that care needs can be met in the next, less intensive, setting.

There is no consensus regarding appropriate timing for transition to less intensive care. Determining an adequate period for assessment of progressive recovery in a patient who has a DoC can be difficult given that meaningful function can be regained for as long as 10 years post-injury.²² The ability to continuously monitor clinical changes and revise the rehabilitation treatment plan accordingly requires the greatest degree of multidisciplinary expertise and coordination, whereas the provision of ongoing rehabilitation treatments is feasible in many post-acute settings. Thus, transition to less intense settings should occur when the need for specialized evaluation and treatment slows. Standardized rating scales should be used to assist in determining the pace and trajectory of recovery.^{74,75} As medical acuity and rehabilitation needs diminish, lower-intensity skilled nursing, outpatient or home-based services can be provided.⁷⁶⁻⁷⁸ In view of the high burden of comorbidities and variable time frame for their resolution,^{79,80} the

capacity of a post-acute setting to manage the patient's medical needs should be carefully assessed. The patient's family should be included in all phases of disposition planning to help ensure that a cohesive plan that supports access to needed services is available after discharge.⁸¹ When an appropriate placement cannot be facilitated, clinicians retain a "duty to treat" until one can be found.

How should rehabilitation care be transitioned when transferring patients to a less intensive level of care?

Recommendation 18: A procedure should be in place to ensure that professional and lay caregivers have the necessary information to continue care. At a minimum, the information communicated should include current level of consciousness, level of functioning, prognosis, comorbid medical conditions, current interventions, equipment needs, caregiver educational needs, and recommendations for follow-up with appropriate specialists.

Achieving successful continuity of care following institutional transfer is dependent upon efficient communication of information integral to health maintenance and functional recovery. Responsibility for effective communication is shared between the healthcare provider, family caregiver and patient (when possible).⁸² A structured, individualized discharge plan can significantly reduce readmission rates.⁸³ At a minimum, the discharge summary should include current diagnosis, level of awareness, degree of assistance required for daily care, prognosis for further recovery, comorbid medical conditions requiring continued treatment and follow-up testing, prescribed medical and rehabilitative interventions (e.g., laboratory and radiology results, dietary restrictions, wound care instructions, weight-bearing status) and equipment needs. Information should be provided in understandable language and should include contact information for local agencies and community support groups.⁸⁴⁻⁸⁷

How should caregiver education and support needs be addressed in the rehabilitation setting?

Recommendation 19: Procedures should be in place to identify caregiver needs and provide individualized education and training to caregivers about level of consciousness, prognosis, care needs, estimated length of stay, financial assistance and community resources and appropriate disposition sites.

Recommendation 20: Resources about the common emotional, legal and financial needs of caregivers and procedures for accessing community-based services (e.g., registries listing mental health providers, attorneys specializing in legal rights for persons with disability and financial consultants) for those who require more intensive services should be available on-site.

Caregivers of patients who have DoC face medical, legal, financial and emotional challenges for which most are unprepared.⁸⁸⁻⁹² Brain injury is sudden and caregiver knowledge of the consequences and course of severe brain injury is limited.⁹³ DoC programs should adopt an approach to caregiver education, training and support that addresses informational, instrumental and emotional needs. *Informational needs* should focus on general health status, level of consciousness, care needs, prognosis and financial responsibilities.⁸⁸ *Instrumental needs* should be addressed through hands-on training to help caregivers manage everyday care.⁹⁰ *Emotional needs* should be approached through direct provision of social support and referral to state and community agencies that provide social services.⁹⁰

To assist caregivers in accessing appropriate resources, facilities should have information on-site for health entitlement programs that provide services to patients who have DoC and their families. Access to these resources can help alleviate the burden of long-term care.⁴⁸ Program

staff should also be aware of state laws governing surrogate decision-making relative to healthcare and estate issues.

Management of Ethical Issues

What policies and procedures should be available to assist with the identification and reconciliation of ethical issues that may arise during the course of rehabilitation?

Recommendation 21: Policies and procedures should be in place that address identification of decision-making surrogates, guardianship, determination of DNR status, use of palliative care pathways, withdrawal of life-sustaining treatment and when ethics consultations should be obtained.

The care of patients who have DoC involves complex ethical questions. Competing ethical values must be weighed, including respect for autonomy (i.e., right to make personal healthcare decisions without undue provider influence), beneficence (i.e., protection of vulnerable persons), non-maleficence (i.e., do no harm), and justice (i.e., appropriate use of limited medical resources).⁹⁴ Programs should create a culture of openness to discuss healthcare ethics. Healthcare team members should know the codes of ethics promulgated by their own professional organizations as well as those of other professions. Policies and procedures should be in place to address ethical concerns that are likely to arise during the delivery of care. At a minimum, policies should provide guidance on circumstances necessitating engagement of an ethics committee or healthcare ethics consultant. DoC program providers should also be aware of institutional policies and procedures concerning adjudication of ethical issues, including:

- *Deciding who can act as a surrogate decision-maker, particularly under conditions of ambiguity and conflict.*⁹⁴

- *Managing advance directives, do-not-resuscitate (DNR) orders and requests for termination of life-supporting measures in the absence clearly-documented advance directives.*^{95,96}
- *Determining whether and when to incorporate palliative care.*⁹³
- *Responding to complaints of neglect, abuse or exploitation.*
- *Determining the conditions under which treatments without a well-accepted evidence-base should be implemented.*⁹⁷⁻⁹⁹

Conclusion

Many persons who have DoC have potential to regain consciousness and functional independence, but recovery depends on receiving high quality multidisciplinary rehabilitation. Programs that provide services to persons who have DoC should be able to, 1) accurately assess sensory and cognitive functions to reduce the high rate of misdiagnosis; 2) systematically monitor rate of functional change to aid prognostic assessment and treatment planning; 3) identify and treat medical comorbidities that may hinder recovery; 4) prevent common complications; and 5) provide caregiver training and support. The evidence-informed, consensus-based recommendations provided here for programs that offer such care, and for payors and caregivers seeking care, describe the essential program structures and processes needed to address the specialized needs of this population.

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Appendix 1

Minimum Competency Recommendations for Programs that Provide Rehabilitation Services for
Persons with Disorders of Consciousness

The Audit Checklist is a tool that was developed for providers, payors and consumers who wish to assess a DoC program's compliance with the minimum competency recommendations proposed by the ACRM-NIDILRR Workgroup. The Checklist specifies the procedures, assessment schedule and professional disciplines required to provide evidence-informed patient care and to conduct program evaluation. This tool is not intended to prescribe specific methods for implementing the recommendations, but rather seeks to ensure that critical areas of care are addressed and reviewed on a regular basis by appropriate personnel. The Checklist can be used at the program level (for program evaluation) or for an individual patient (for care planning) and may be modified as needed.

Audit Checklist			
Diagnostic and Prognostic Assessment			
Recommendation 1: Specialized programs for patients with DOC should adopt a systematic approach to diagnostic and prognostic assessment that relies on a careful review of the history, recent structural imaging data, and serial testing with validated behavioral measures.	Procedure	Schedule	Discipline
	<input type="checkbox"/> H & P completed and identifies potential medical complications and confounds that may mask awareness or slow recovery	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> CT or MRI results obtained/reviewed to identify reversible complications that may mask awareness or slow recovery	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Other
	<input type="checkbox"/> LoC assessed using standardized measure validated	<input type="checkbox"/> On admission <input type="checkbox"/> Daily	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych

	for DoC	<input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> Serial testing performed (at least 5 exams)	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 2:</p> <p>Differential diagnosis among disorders of consciousness (i.e., coma, vegetative state, minimally conscious state) should be based on published, evidence-based guidelines which rely on diagnostic procedures that have acceptable reliability and validity and consider common confounding factors such as sedating treatments and underlying sensory, motor, or cognitive impairments.</p>	<input type="checkbox"/> AAN-ACRM-NIDILRR practice guidelines for management of patients with DoC consulted and applied where indicated	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> Medication regimen reviewed to identify sedating medications	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD
	<input type="checkbox"/> Protocols established to identify underlying sensory, motor or cognitive impairments	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

<p>Recommendation 3:</p> <p>Prognostication in patients with DOC should consider the best available evidence. When formulating prognosis, one must consider predictors used, outcome of interest, time post-injury when the predictor is applied, time post-injury when the outcome of interest will be assessed and degree of precision associated with the prognostic forecast.</p>	<input type="checkbox"/> Procedures in place to identify and update relevant outcomes and prognostic indicators	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 4:</p> <p>Communication of diagnosis and prognosis should ensure that the clinical information provided (i.e., diagnostic features, prognostic indicators) is understandable and the limits of certainty afforded by the available evidence is described.</p>	<input type="checkbox"/> Evaluation process conducted to assess satisfaction with diagnostic and prognostic information provided during family conferences	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
Treatment			
<p>Recommendation 5:</p> <p>Rehabilitation services in a DOC program should be provided by a multidisciplinary team of brain injury professionals whose members include, but are not limited to, physicians, psychologists, physical therapists, occupational therapists, speech therapists, nurses, and social workers, and whose efforts are focused on individualized cross-disciplinary treatment goals that enhance health, mobility, self-care, communication and participation.</p>	<input type="checkbox"/> Team includes physicians, nursing, PT, OT, SLP, psychology, neuropsychology, case mgt, social svc <input type="checkbox"/> Team meets for regular team meetings and/or dedicated DoC rounds to discuss DoC specific problems, progress, treatment plan and goals	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

<p>Recommendation 6:</p> <p>An attending physician must be available on-site at least 5 days per week (with continuous on-call coverage) to oversee medical management; programs that accept patients on ventilators should additionally have a specialist in pulmonology on site. The program should have established procedures for obtaining timely consultations from consultants in additional specialties not represented by the attending physician, including internal medicine, physiatry, neurology, neurosurgery, infectious disease, gastroenterology, ophthalmology, and otolaryngology, and established relationships with specialists in each of these areas. Standard procedures must be in place to transfer patients with severe or life-threatening conditions to acute care or ICU services emergently.</p>	<input type="checkbox"/> Attending is available on site, full time at least 5 days per week <input type="checkbox"/> On-site medical care and/or consultations available by key specialties – physiatry, internal medicine, neurology, pulmonary or ENT, <input type="checkbox"/> Other off-site specialty care available as needed – ophthalmology, neurosurgery, orthopedics, infectious disease, gastroenterology, and others <input type="checkbox"/> Emergency services available, nearest facilities identified <input type="checkbox"/> Neuroimaging, EEG services available	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 7:</p> <p>Care regimens intended to promote physical health and mitigate complications should be initiated immediately upon admission, updated at least weekly and streamlined where possible to reduce the burden of future care. At a minimum, these regimens should focus on adequate nutrition; respiratory hygiene and aspiration risk; bladder and bowel management; skin integrity; contracture prevention, positioning and tone management; prevention of</p>	<input type="checkbox"/> Nutritional assessment (g-tube checks; feeding formula; calorie assessment) <input type="checkbox"/> Tracheostomy evaluation (trach change, capping, PM valve, decannulation) <input type="checkbox"/> Skin checks	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly <input type="checkbox"/> On admission <input type="checkbox"/> Weekly <input type="checkbox"/> On admission <input type="checkbox"/> daily	<input type="checkbox"/> dietician <input type="checkbox"/> nursing <input type="checkbox"/> MD <input type="checkbox"/> MD <input type="checkbox"/> ENT or Pulmonary <input type="checkbox"/> SLP <input type="checkbox"/> nursing <input type="checkbox"/> nursing <input type="checkbox"/> MD

thrombophlebitis; and optimizing sleep/wake patterns.	<input type="checkbox"/> Positioning schedule	<input type="checkbox"/> On admission <input type="checkbox"/> daily	<input type="checkbox"/> nursing
	<input type="checkbox"/> Tone management, ROM, contracture management	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> OT <input type="checkbox"/> PT
	<input type="checkbox"/> DVT prevention	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD
	<input type="checkbox"/> Assessment sleep / wake	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> nursing
<p>Recommendation 8:</p> <p>On admission, a comprehensive neurosensory examination should be performed to evaluate for previously unrecognized hearing, visual, somatosensory and motor impairments; prescribed medications should be reviewed so those with potentially sedating properties can be stopped or replaced with less sedating alternatives where possible; and brain imaging studies to define residual neuropathology and screen for late complications should be reviewed and updated if appropriate.</p>	<input type="checkbox"/> Expert diagnostic assessment of potential auditory, visual and somatosensory perceptual capacity or language processing capacity is conducted on all patients. This may be based on examination findings and other diagnostic information, including neuroimaging and electrophysiological testing, if available, that might indicate damage to peripheral or central sensory structures or sensory processing network pathways. Review of medications for any that are potentially sedating is conducted.	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych
<p>Recommendation 9:</p> <p>Programs should have protocols that initiate</p>	<input type="checkbox"/> There are procedures in place to report declines or plateaus in	<input type="checkbox"/> Other: as needed and indicated	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych

<p>timely medical evaluation in response to a decline or plateau in clinical status and function, or in the presence of clinical conditions that present risks for worsened outcomes. These evaluations should address possible disorders including new intracranial complications, subclinical seizures, occult infections, metabolic disturbances, or adverse medication effects, and will typically entail neuroimaging, electrophysiological assessments, laboratory studies, and/or comprehensive medication review.</p>	<p>clinical status and function or concerns about clinical conditions that may affect recovery to responsible medical clinicians. This should initiate consideration of pertinent diagnostic assessment and management.</p>		<input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 10:</p> <p>Environmental factors (e.g., positioning, lighting, time of day, level of stimulation, distractions and restraint) that may influence arousal and neurocognitive performance should be systematically evaluated for their impact on behavior.</p>	<input type="checkbox"/> There is a structured approach to prompting team discussion of environmental influences on individual patient performance	<input type="checkbox"/> On admission <input type="checkbox"/> daily	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> When concerns about environmental influences on performance arise, there is a mechanism for evaluating them.		<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

<p>Recommendation 11:</p> <p>Pharmacologic or other interventions that have been systematically reviewed and found to be efficacious in enhancing arousal, behavioral responsiveness or rate of recovery should be strongly considered when developing a plan of care. Other interventions, whose efficacy or ineffectiveness has not been determined in such studies, can be considered for use when the risk of adverse effects is low and a reasonable plan is in place to determine the positive and negative effects of treatment in the individual.</p>	<input type="checkbox"/> List of efficacious medications is current and available to treating physicians, with a plan for regular updating	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> Other
	<input type="checkbox"/> When off-label medications are used, a feasible plan is documented in the medical record for assessing adverse effects and positive impact.	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> Other
<p>Recommendation 12:</p> <p>A variety of strategies, technologies and adaptive equipment should be available to enhance the detection of emerging neurobehavioral capacities and augment their transformation into functional abilities such as communication and environmental interactions. There should be a systematic approach to assessment of patient capacities that can guide selection of appropriate technology, and an approach to assessing the functional impact of the technology selected.</p>	<input type="checkbox"/> Listing of available high and low tech devices for augmenting function is accessible to clinical staff and there is a strategy for training new staff in their use	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> Where augmentative technology is provided, there is documentation of pre-assessment of the patient's necessary cognitive and motor capacities, and of post-assessment of the technology's functional impact.	<input type="checkbox"/> On admission <input type="checkbox"/> Weekly	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> PT <input type="checkbox"/> OT <input type="checkbox"/> SLP <input type="checkbox"/> Other
<p>Recommendation 13:</p> <p>When monitoring recovery in individual patients,</p>	<input type="checkbox"/> Regular behavioral assessment with a validated measurement tool is performed	<input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> PT

<p>validated measures should be used to establish level of performance at baseline, rate and trajectory of recovery, degree of disability, and response to individualized treatment. The frequency of assessment and review of results should be sufficient to address the question(s) of interest.</p>	on all patients		<input type="checkbox"/> OT <input type="checkbox"/> SLP <input type="checkbox"/> Other
	<input type="checkbox"/> The frequency of assessment is tailored to the length of stay and range of recovery rates in the program		
	<input type="checkbox"/> There is a structured process for designing the measurement strategy for assessing the effects of individual treatment interventions		<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> PT <input type="checkbox"/> OT <input type="checkbox"/> SLP <input type="checkbox"/> Other
<p>Recommendation 14:</p> <p>DOC programs should have a well-defined plan for staff education and training to ensure that assessment and treatment interventions designed for patients and caregivers address primary areas of need and are based on the best available evidence</p>	<input type="checkbox"/> Administration and site leadership define educational needs of the DOC team	<input type="checkbox"/> <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> Administration and site leadership define discipline specific needs	<input type="checkbox"/> <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Other
	<input type="checkbox"/> Administration and site leadership provide resources and educational opportunities for DOC based training	<input type="checkbox"/> <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

<p>Recommendation 15:</p> <p>Systems for quality improvement (QI) that rely on consistent assessment measures and pre-specified performance benchmarks should be in place. Review of QI data should be performed at least twice each year. QI measures may include commercially available assessments, locally-developed assessments, or a combination of both. Program performance benchmarks should be established to address patient outcomes, caregiver needs, and operational program processes.</p>	<input type="checkbox"/> Administration and medical executive leadership provides infrastructure and resources to evaluate medically and functionally applicable outcomes, program processes and caregiver needs.	<input type="checkbox"/> <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
	<input type="checkbox"/> Procedures in place to select QI measures, set benchmarks, collect and review data.	<input checked="" type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
Transitioning Care/Long Term Care Needs			
<p>Recommendation 16:</p> <p>When patients in DOC programs demonstrate recovery of consciousness, treatment goals should shift to support rehabilitation interventions designed to promote greater independence in mobility, self-care, communication and other functional goals</p>	<input type="checkbox"/> Procedures in place to identify and update relevant person specific outcomes and linkage to acute rehabilitation care	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 17:</p> <p>After an adequate period of assessment, transition to a less intensive care setting should occur when the pace of change suggests that functional abilities, rehabilitation goals, and medical needs are not changing substantially or anticipated to change in the near-term and that care needs can be met in the next, less intensive, setting</p>	<input type="checkbox"/> Evaluation process conducted to assess progress and linkage to experienced long term care options for persons with DOC	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

<p>Recommendation 18:</p> <p>A procedure should be in place to ensure that professional and lay caregivers have the necessary information to continue care. At a minimum the information communicated should include current level of consciousness, level of functioning, prognosis, comorbid medical conditions, current interventions, equipment needs, caregiver educational needs, and recommendations for follow-up with appropriate specialists</p>	<input type="checkbox"/> Administration and care leadership team provide for meetings and communication of clinical status on an on going basis	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 19:</p> <p>Procedures should be in place to identify caregiver needs and provide individualized education and training to caregivers about level of consciousness, prognosis, care needs, estimated length of stay, financial assistance and community resources and appropriate disposition sites.</p>	<input type="checkbox"/> Administration and care team leadership team provide for meetings, learner self-assessment tools and resources to enhance knowledge regarding level of consciousness, length of stay issues, financial and community resources	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge <input type="checkbox"/> Other	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other
<p>Recommendation 20:</p> <p>Resources about the common emotional, legal and financial needs of caregivers and procedures for accessing community-based services (e.g., registries listing mental health providers, attorneys specializing in legal rights for persons with disability and financial consultants) for those who require more intensive</p>	<input type="checkbox"/> Administration and care team leadership will provide access to community-based resource and legal services	<input type="checkbox"/> On admission <input type="checkbox"/> Daily <input type="checkbox"/> Weekly <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

services should be available on-site.			
Management of Ethical Issues			
<p>Recommendation 21:</p> <p>Policies and procedures should be in place that address identification of decision-making surrogates, guardianship, determination of DNR status, use of palliative care pathways, withdrawal of life-sustaining treatment and when ethics consultations should be obtained.</p>	<p>Administration has developed and disseminated policies and procedures designed to ensure that family caregivers and surrogates have access to on-site resources to assist with bioethical issues that arise during the course of care.</p>	<input type="checkbox"/> On admission <input type="checkbox"/> At discharge	<input type="checkbox"/> MD <input type="checkbox"/> Neuropsych/Psych <input type="checkbox"/> SLP <input type="checkbox"/> OT <input type="checkbox"/> PT <input type="checkbox"/> Other

Appendix 2: Summary of Minimum Competency Recommendations for Programs that Provide Rehabilitation Services for Persons with Disorders of Consciousness.

Diagnostic and Prognostic Assessment
<p>Recommendation 1: Specialized programs for patients with DOC should adopt a systematic approach to diagnostic and prognostic assessment that relies on a careful review of the history, recent structural imaging data, and serial testing with validated behavioral measures.</p>
<p>Recommendation 2: Differential diagnosis among disorders of consciousness (i.e., coma, vegetative state, minimally conscious state) should be based on published, evidence-based guidelines rely on diagnostic procedures that have acceptable reliability and validity and consider common confounding factors such as sedating treatments and underlying sensory, motor, or cognitive impairments.</p>
<p>Recommendation 3: Prognostication in patients with DOC should consider the best available evidence. When formulating prognosis, one must consider:</p> <ul style="list-style-type: none"> (a) Predictors used (b) Outcome of interest (c) Time post-injury when the predictor is applied (e.g., 2 weeks, 3 months, 60 months) (d) Time post-injury when the outcome of interest will be assessed (e.g., 6 months, 12 months, 60 months) (e) Degree of precision associated with the prognostic forecast
<p>Recommendation 4: Communication of diagnosis and prognosis should ensure that the clinical information provided (i.e., diagnostic features, prognostic indicators) is understandable and the limits of certainty afforded by the available evidence is described.</p>
Treatment
<p>Recommendation 5: Rehabilitation services in a DOC program should be provided by a multidisciplinary team of brain injury professional whose members include, but are not limited to, physicians, psychologists, physical therapists, occupational therapists, speech therapists, nurses, and social workers, and whose efforts are focused on individualized cross-disciplinary treatment goals that enhance health, mobility, self-care, communication and participation.</p>
<p>Recommendation 6: An attending physician must be available on-site at least 5 days per week (with continuous on-call coverage) to oversee medical management; programs that accept patients on ventilators should additionally have a specialist in pulmonologist on site. The program should have established procedures for obtaining timely consultations from consultants in additional specialties not represented by the attending physician, including internal medicine, psychiatry, neurology, neurosurgery, infectious disease, gastroenterology, ophthalmology, and otolaryngology, and established relationships with specialists in each of these areas. Standard procedures must be in place to transfer patients with severe or life-threatening conditions to acute care or ICU services emergently.</p>

Recommendation 7:

Care regimens intended to promote physical health and mitigate complications should be initiated immediately upon admission, updated at least weekly and streamlined where possible to reduce the burden of future care. At a minimum, these regimens should focus on adequate nutrition; respiratory hygiene and aspiration risk; bladder and bowel management; skin integrity; contracture prevention, positioning and tone management; prevention of thrombophlebitis; and optimizing sleep/wake patterns.

Recommendation 8:

On admission, a comprehensive neurosensory examination should be performed to evaluate for previously unrecognized hearing, visual, somatosensory and motor impairments; prescribed medications should be reviewed so those with potentially sedating properties can be stopped or replaced with less sedating alternatives where possible.; and brain imaging studies to define residual neuropathology and screen for late complications should be reviewed and updated if appropriate.

Recommendation 9:

Programs should have protocols that initiate timely medical evaluation in response to a decline or plateau in clinical status and function, or in the presence of clinical conditions that present risks for worsened outcomes. These evaluations should address possible disorders including new intracranial complications, subclinical seizures, occult infections, metabolic disturbances, or adverse medication effects, and will typically entail neuroimaging, electrophysiological assessments, laboratory studies, and/or comprehensive medication review.

Recommendation 10:

Environmental factors (e.g., positioning, lighting, time of day, level of stimulation, distractions and restraint) that may influence arousal and neurocognitive performance should be systematically evaluated for their impact on behavior.

Recommendation 11:

Pharmacologic or other interventions that have been systematically reviewed and found to be efficacious in enhancing arousal, behavioral responsiveness or rate of recovery should be strongly considered when developing a plan of care. Other interventions, whose efficacy or inefficacy has not been determined in such studies can be considered for use when the risk of adverse effects is low, and a reasonable plan is in place to determine the positive and negative effects of treatment in the individual.

Recommendation 12:

A variety of strategies, technologies and adaptive equipment should be available to enhance the detection of emerging neurobehavioral capacities and augment their transformation into functional abilities such as communication and environmental interactions. There should be systematic approach to assessment of patient capacities that can guide selection of appropriate technology, and an approach to assessing the functional impact of the technology selected.

Recommendation 13:

When monitoring recovery in individual patients, validated measures should be used to establish level of performance at baseline, rate and trajectory of recovery, degree of disability, and response to individualized treatment. The frequency of assessment and review of results should be sufficient to address the question(s) of interest.

Recommendation 14:

DOC programs should have a well-defined plan for staff education and training to ensure that assessment and treatment interventions designed for patients and caregivers address primary areas of need and are based on the best available evidence.

Recommendation 15:

Systems for quality improvement (QI) that rely on consistent assessment measures and pre-specified performance benchmarks should be in place. Review of QI data should be performed at least twice each year. QI measures may include commercially available assessments, locally-developed assessments, or a combination of both. Program performance benchmarks should be established to address patient outcomes, caregiver needs, and operational program processes.

Transitioning Care/Long Term Care Needs**Recommendation 16:**

When patients in DOC programs demonstrate recovery of consciousness, treatment goals should shift to support rehabilitation interventions designed to promote greater independence in mobility, self-care, communication and other functional goals.

Recommendation 17:

After an adequate period of assessment, transition to a less intensive care setting should occur when the pace of change suggests that functional abilities, rehabilitation goals, and medical needs are not changing substantially or anticipated to change in the near-term and that care needs can be met in the next, less intensive, setting.

Recommendation 18:

A procedure should be in place to ensure that professional and lay caregivers have the necessary information to continue care. At a minimum the information communicated should include current level of consciousness, level of functioning, prognosis, comorbid medical conditions, current interventions, equipment needs, caregiver educational needs, and recommendations for follow-up with appropriate specialists.

Recommendation 19:

Procedures should be in place to identify caregiver needs and provide individualized education and training to caregivers about level of consciousness, prognosis, care needs, estimated length of stay, financial assistance and community resources and appropriate disposition sites.

Recommendation 20:

Resources about the common emotional, legal and financial needs of caregivers and procedures for accessing community-based services (e.g., registries listing mental health providers, attorneys specializing in legal rights for persons with disability and financial consultants) for those who require more intensive services should be available on-site.

Management of Ethical Issues**Recommendation 21:**

Policies and procedures should be in place that address identification of decision-making surrogates, guardianship, determination of DNR status, use of palliative care pathways, withdrawal of life-sustaining treatment and when ethics committee consultations should be obtained.

Appendix 3. Definitions of key terms and abbreviations.

Term	Definition
Coma	A state of complete unconsciousness in which there is no evidence of wakefulness (i.e., eyes remain continuously closed) or self or environmental awareness.
Caregiver	A family member or paid assistant who takes care of a sick or disabled person
Disorder of consciousness (DoC)	A transient or permanent disturbance in arousal and behavioral responsiveness caused by acquired brain injury.
Do not resuscitate (DNR)	An order written by a medical doctor that instructs health care providers not to perform life-saving procedures, including cardiopulmonary resuscitation (CPR), when a patient's breathing or cardiac function stops.
Healthcare provider	A physician, psychologist, nurse, social worker or allied health professional (eg, physical therapist) who is authorized to provide healthcare services within the scope of their practice as defined by state law.
Minimally conscious state (MCS)	Condition of severely altered consciousness in which there is definite, but often subtle and inconsistent, behavioral evidence of self or environmental awareness.
Multidisciplinary team	A group of healthcare professionals from different disciplines who work together to develop a plan of care intended to achieve a common set of treatment goals.
Payor	An insurance company authorized to review and approve healthcare service requests and expenses.
Post-traumatic amnesia	A state of confusion caused by traumatic brain injury that is characterized by disorientation and inability to remember events that occurred after the injury.
Quality improvement (QI)	A framework used to systematically improve the way health care is delivered to patients.
Rancho level	A reference to one of eight stages of cognitive and behavioral recovery that occur after brain injury and are described on the Rancho Los Amigos Levels of Cognitive Functioning Scale.
Recovery of consciousness	Reemergence of reproducible behavioral evidence of at least one feature of MCS, signaling the transition from coma or VS/UWS to MCS.
Vegetative state (VS), unresponsive wakefulness syndrome (UWS)	Spontaneous eye-opening signaling wakefulness, but no evidence of purposeful behavior suggesting awareness of self or environment